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A cross sectional study to understand socio demographic profile of patients of sickle cell anemia in a Taluka of South Gujarat

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ABSTRACT

Background: India has the largest concentration of tribal populations globally. A high prevalence of sickle cell anemia is seen in tribal communities of South Gujarat. The aims and objectives were to study socio-demographic profile of the patients having positive sickle cell status.

Methods: It was a cross-sectional study, where Bardoli taluka was selected purposively. All patients of sickle cell anemia registered at all PHCs of Bardoli Taluka during period between June 2010 and May 2011 & aged between 18 to 30 years were taken in study.

Results: This study included total 276 cases of which 264 (96%) had sickle cell trait, while 12 (4%) had sickle cell disease. Majority of patients were from Umrakh and Vanskui PHC. More than 90% of patients belonged to ST caste and more than 40% among them were from Rathod sub caste.

Conclusions: More than 90% of patients were laborers and majority of them belonged to low socio economic class. Mean age at diagnosis of sickle cell anemia ranged from 21 to 25 years.

Keywords: Sickle cell anemia, Cross sectional study, Socio-demographic profile

INTRODUCTION

Sickle-cell disease (SCD), also known as sickle-cell anaemia (SCA) and drepanocytosis, is a hereditary blood disorder, characterized by an abnormality in the oxygen carrying haemoglobin molecule in red blood cells. This leads to a propensity for the cells to assume an abnormal, rigid, sickle-like shape under certain circumstances. Sickle-cell disease is associated with a number of acute and chronic health problems, such as severe infections, attacks of severe pain ("sickle-cell crisis"), and stroke, and there is an increased risk of death. Sickle-cell disease occurs when a person inherits two abnormal copies of the haemoglobin gene, one from each parent. Several subtypes exist, depending on the exact mutation in each haemoglobin gene. A person with a single abnormal copy

does not experience symptoms and is said to have sicklecell trait. Such people are also referred to as carriers.¹

Almost 300,000 children are born with a form of sickle-cell disease every year, mostly in sub-Saharan Africa, but also in other parts of the world such as the West Indies and in people of African origin elsewhere in the world. In 2013 it resulted in 176,000 deaths up from 113,000 deaths in 1990.²

India has the largest concentration of tribal populations globally. They are believed to be the early settlers in the country and are considered to be the original inhabitants. According to the Census of India 2011, the tribal population of India is 8.6 per cent of the total population which is about 67.8 million people. The states of Madhya Pradesh, Maharashtra, Odisha, Gujarat, Rajasthan,

Jharkhand, Chhattisgarh, Andhra Pradesh, West Bengal and Karnataka account for around 83 per cent of the total scheduled tribe population in the country and majority of these tribal groups live in rural areas.³

The first description of sickle haemoglobin in India was by Lehman and Cutbush in 1952 in the tribal populations in the Nilgiri hills in south India.⁴ In the same year, Dunlop and Mazumder also reported the presence of sickle haemoglobin in the tea garden workers of Upper Assam who were migrant labourers from tribal groups in Bihar and Odisha.⁵

In Gujarat, the Dhodia, Dubla, Gamit, and Naika tribes have a high prevalence of HbS (13-31%). More recently very extensive population surveys have been done by the Indian Red Cross Society, Gujarat State Branch where 1,68,498 tribals from 22 districts were screened and the overall prevalence of sickle cell carriers was 11.37 per cent. Some tribal groups in south Gujarat like Chaudry, Gamit, Rohit, Vasava and Kukana have shown both a high prevalence of HbS (6.3 to 22.7%) as well as β -thalassaemia trait (6.3 to 13.6%). These tribal groups would have the likelihood of co-inheriting both these genes.

So to combat against this disease we need to focus on this tribal population. Major steps for prevention is to carry out various programs, surveys, educating and increasing awareness among the people so that maximum active participation is from population can be achieved which is very vital. Success cannot be achieved without people is being actively involved and show willingness towards limiting the disease and its consequences including morbidity and mortality which can improve quality of life among this people. For that, it is necessary to know the socio-demographic profile of this tribal population.

Aims and objectives of study

To study socio- demographic profile of the patients having positive sickle cell status.

METHODS

It was a cross sectional study carried out in Bardoli Taluka, which is a town in South Gujarat of Surat district and is in the list of scheduled areas of Gujarat.⁹

Study was carried out between July 2012 to December 2012, in which sampling was carried out conveniently in Bardoli Taluka of Surat district. All Sickle cell disease affected patients between 18 to 30 years registered in all PHCs of Bardoli taluka during the period between June 2010 to May 2011 were included in study. Total study participants came out to be 276, which included both sickle disease and sickle trait. This information was gathered from Surat District Panchayat. Sickle cell disease affected patients not in the age group of 18 to 30 years were excluded from the study. Those not willing to

participate were also excluded from the study. A pretested semi structured questionnaire was used to take interview of the participants. All the study participants were contacted telephonically. They were either interviewed at their home or at PHCs. All those who were approached gave verbal consent to be part of study Data was collected regarding socio demographic profile of them including various variables like sex, education, religion, occupation, socioeconomic status etc.

Data was entered in MS office Excel 2007, and was analyzed using Epi Info 7 and relevant frequencies, proportions and percentages were calculated.

RESULTS

This study included total 276 cases of which 264 (96%) had Sickle Cell Trait, while 12 (4%) had sickle cell disease.

Table 1 shows that more than 50% of the study participants were from Vanskui and Umrakh PHCs. Minimum participants were from Kadod and Sarbhon PHCs. Mean age of diagnosis of SCA among study participants was almost 25 years in Vanskui PHC and Umrakh PHC; approximately 24 years in Uva PHC and Varad PHC. The significance of difference of age might be due to low mean age of diagnosis in Sarbhon PHC and Vankaner PHC (around 23 years) and / or in Kadod PHC (just about 21 years). It may due to operational aspect that the Sarbhon, Vankaner and Kadod PHCs might have been running the Mass Campaign more effectively than other PHCs.

Table 2 shows that more than half of the study participants belonged to age groups between 27 to 30 years. The distribution of the study participant was skewed towards female with Male to Female ratio of 1:1.7. Majority (93%) belonged to scheduled tribe category showing preponderance of sickle cell anemia. Most (94%) of the study participants were involved in labour work. Caste and occupation illustrated partly their Socio-economic condition. All the participants were reportedly following Hindu religion.

Table 3 shows that more than 42% of study participants belonged to Rathod community and 33% belonged to Chaudhari community, 12% to Halpati and the remaining study participants comprised of Halpati, Gamit, Vasava, Parmar etc. Figure 4 shows the same. So it is clear that there is preponderance of sickle cell anemia in Rathod Sub caste in Bardoli Taluka.

Table 4 shows that majority of study participants (about 60%) were educated up to primary level and about 26% were educated up to secondary level. Only 6% of study participants were illiterate. More than 80% of participants in this study were from BPL. More than 75% participants in this study were married and only about 20% were unmarried.

Table 1: PHC wise distribution of the study participants and their mean age of diagnosis at PHCs.

	PHCs						
	Kadod	Uva	Umrakh	Vanskui	Varad	Sarbhon	Vankaner
Frequency	10	39	65	72	48	16	28
	Mean age at diagnosis						
Mean Age (years) ± SD	21.4 ± 4.1	24.0±3.9	24.9 ± 3.7	24.5 ± 3.5	24.4±3.5	22.6 ± 3.4	22.6± 2.9

F statistic=3.04, p value=0.006.

Table 2: Distribution of study participants according to biological and social variables.

	Age group (years)					
	18-22 years	23-26 years		27-30 years		
Frequency (%)	17 (6.2)	114 (41.3) 145 (52.5)				
	Gender					
	Male	Female				
Frequency (%)	102 (36.9)	174 (63.1)				
	Caste					
	ST	SC	SEBC	Others		
Frequency (%)	256 (92.8)	16 (5.8)	1 (0.3)	3 (1.1)		
	Occupation					
Laborer		Housework	Housework		Others	
Frequency (%)	260 (94.2)	8 (2.9)		8 (2.9)		

Table 3: Distribution of study participants according to sub caste (N=276).

Sub caste	Percentage (%)
Rathod	41.6
Chaudhari	33.3
Halpati	12.3
Others (Vasava, Gamit, Dhodia, Parmar, Solanki, Nayka, Kokni, Maisuria, More, Valvi, Kotwadia, Katariya, Padvi)	13.0

Table 4: Distribution of study participants according to level of education, socio economic status and marital status.

	Education					
	Illiterate	Primary	Secondary	Higher Secondary	Graduate	
Frequency (%)	18 (6.5)	168 (60.9)	71 (25.7)	12 (4.3)	7 (2.5)	
Socio-economic status						
	APL BPL					
Frequency (%)	49 (18)	227 (82)				
	Marital Status					
	Married	Unmarried	Sepa	arated	Widowed	
Frequency (%)	215 (77.9)	59 (21.4)	1 (0.	.4)	1 (0.4)	

DISCUSSION

The population of Gujarat has crossed 6 crores as per Census 2011.³ 14.79% of the population in Gujarat is tribal¹⁰. Out of total 26 districts of Gujarat; more than half are tribal districts. Gujarat is the 4th most schedule tribe populated state of India after Madhya Pradesh, Maharashtra and Orissa. The tribal community of Gujarat inhabitants in the geographically difficult terrains of the Eastern belt, extending from Ambaji in the North to Dang in the South Southern Gujarat includes districts of Dangs,

Valsad, Navsari, Surat and Bharuch. ¹¹ The population of Bardoli Taluka was 2,10,789 according to census 2001. ¹² Out of which, 99213 (47%) of the population belonged to Scheduled Tribe. ¹³ The incidence of genetic disorders that cause severe anaemia, including thalassemia and sickle cell disease, is the highest in Gujarat. This is the finding of a recent study conducted on samples taken from different states by the sickle cell anaemia control programme supported by the Gujarat government. Of the samples from Gujarat examined for the study, 34% were found to have sickle cell anaemia. ¹⁴ In the year 2005-

2006, Department of Health & Family Welfare of Government of Gujarat passed a resolution No. S.C.K.-102005, New Matter-10-G dated 30th January 2006, to initiate sickle cell anaemia control program in the 4 districts of south Gujarat. 15 As a part of strategy of sickle cell anaemia control programme, mass sickle cell screening was taken up by Government of Gujarat. This study is an effort to reach people in the community mostly in tribal areas, consisting of people in the age group of 18-30 years, who carry abnormal sickle cell gene, and are either suffering from sickle cell trait or from sickle cell disease. With this frame in mind, Bardoli Taluka of Surat district was selected purposively. Age group of 18 to 30 years was selected for study because sickle cell anaemia is a hereditary disorder, people in the age group of 18-30 years, who carry abnormal gene, are most likely to transmit the same gene to their future generation when they get married. Out of 276 participants, 264 of them had sickle cell trait, while 12 had sickle cell disease. So, 4% of study population had sickle cell disease.

Total list of 276 participants were retrieved from Surat district Panchayat. Among them, 72 participants were from Vanskui PHC, While 65 were from Umrakh PHC. Minimum participants (16 and 10) were from Sarbhon PHC and Kadod PHC respectively. This might be due the fact that Vanskui and Umrakh comprises mainly of tribal population, while Kadod and Sarbhon have less tribal areas.

In the present study, out of 276 participants, 174 were female, which comprised of 63% of the total study population. While in the study done by Awasthy et al in safdarjang hospital, Delhi, male and female comprised of equal participants. Contrary findings were observed by Kamble et al in their study, where male to female ratio was 1.65:1. May be, the reason for this is, in the present study, because, majority of patients were diagnosed during mass screening, which is usually carried out during day time, males were unable to attend mass screening program, because the majority of them were labourers. ¹⁷

Out of 276 participants, more than 90% of them belonged to Scheduled Tribes. When the prevalence of SCA in different sub castes was taken into account, more than 40% belonged to Rathod community and 33% belonged to Chaudhari community, and the remaining study participants comprised of Halpati, Gamit, Vasava, Parmar etc. Similar findings were observed by Neena et al in their study conducted at Pipalwada, Gujarat, where also the prevalence of SCA was found to be highest in Rathod community. Saxena in his study reported prevalence of sickle cell anemia among Vasava was 26.4%, Chaudhari 21.4%, Gamit 20%, Panchal 13.8% and among Rathod was 8.3%. These observations support the hypothesis that the sickle cell disorders are present in scheduled tribes, and not found in so called higher castes.

Among all study participants, more than 80% belonged to below poverty line family. As such, the proportions of people living below poverty line are more in scheduled tribes as compared to other castes. Similar findings were observed by Dubey et al in his study.¹⁹ This shows that majority of the patients that will suffer from sickle cell anemia in future will also belong to poor economic class (assuming that in majority of the cases there occurs no dire changes in the social class in the future generation), and because of this they might not be able to avail or rather utilize the available services for them because of ignorance that is going to be common in low income people. This leaves us with the option of prevention rather than treatment in which their compliance as well as the outcome is going to be poor. Moreover, the expenditure before the future sickle cell anemia patients of poor economic class will further make their economic condition worse. Almost 80% of the study participants in the present study were married. So, it was necessary that they have sufficient knowledge regarding hereditary nature of sickle cell anemia. When education level of study participants were taken into account, more than 60% of them completed only primary education. But it was encouraging to know that only 7% of them illiterate. Similar findings were observed by Faisal et al in their study done in Bahrain on sickle cell disease patients, where more than 70% of the patients had low educational level.20

When inquiry was made about the occupation of the study participants, more than 90% of the study participants were laborers. Similar findings were observed by Faisal et al in their study done in Bahrain on sickle cell disease patients, where more than 80% of the patients were laborers.²⁰

Based on socio demographic profile, it is clear that predominantly people belonging to ST caste, low socio economic class and laborers are affected by sickle cell disease and they are the most underserved people of the society and targeting them for IEC for sickle cell disease will be useful.

CONCLUSION

In this study, more than 90% of the study participants affected by sickle cell anemia belonged to ST caste, with Rathod and Chaudhari Subcaste more commonly affected. Mean age of diagnosis of sickle cell anemia at different PHCs ranged from 21 to 25 years. More than 80% of study participants belonged to BPL families and 94% of the participants were laborers.

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Institutional Ethics Committee

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